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**Original Article**

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# *MyCODE*: a prospective evaluation of lay-language molecular tumor board protocols in precision oncology

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## Abstract

***Background:*** **Molecular Tumor Boards (MTBs) are a pillar of precision oncology, integrating results of extended molecular profiling into clinical care. Yet, their protocols are typically incomprehensible for patients. Systematic patient-facing communication has remained limited.**

***Methods:*** **In the single-center study *MyCODE*, individually tailored lay-language MTB protocols were developed based on didactic and psychological principles and prospectively evaluated. Using questionnaires adapted and developed for this task, patients with cancer evaluated their individual protocols and overall experience. Treating physicians were surveyed separately.**

***Results:*** **Forty-three patients were enrolled, 33 (77%; 55% women; median age 65; patients with 10 different cancer entities) returned completed questionnaires. Of those, 82% shared the questionnaire with at least one additional person. Lay-language protocols were perceived as helpful (68% "very," 29% "rather"), well-structured (71% "very," 29% "rather"), and easily comprehensible (63% "very," 31% "rather") by most patients. 85% reported that the protocol improved their understanding of treatment decisions, and 94% perceived them as supportive even if the MTB failed to provide options for precision therapy. Additionally, 13 treating physicians received questionnaires, of which 9 were returned. Responding physicians rated the benefit for patients as high (44%) or very high (44%) and supportive (67%) or rather supportive (33%) for their personal work.**

***Conclusions:*** **Providing patients with lay-language MTB protocols is feasible, accepted, and valued even in the absence of therapeutic options. The *MyCODE* approach seems to enable patient empowerment and to support patients and physicians in shared decision-making in precision oncology.**

**Key words:** precision medicine; molecular tumor board; lay-language summaries; patient communication; patient empowerment; shared decision-making

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**Implications for Practice**

The *MyCODE* study provides first empirical evidence that lay-language MTB protocols are feasible, well accepted, and valuable for both patients and physicians. By translating complex genomic findings into accessible, structured reports, understanding, transparency, and participation in precision oncology are strengthened. Building on these results, the *MyCODE* framework offers a scalable foundation for integrating patient-centered communication into routine practice and future AI-assisted workflows.

# Introduction

Precision oncology aims to provide targeted cancer therapies based on molecular tumor characteristics. Molecular Tumor boards (MTBs) are multidisciplinary platforms for interpreting genomic results and generating individualized treatment recommendations beyond guideline-based care.[1–5] During the last years, standardization of MTBs has developed considerably. Illert et al.[6] demonstrated how the German Network for Personalized Medicine (DNPM) established national frameworks for precision oncology, while Westphalen et al.[5] highlighted implementation challenges and the importance of standardization across MTBs.

MTBs are embedded in routine oncology care but often address treatment options beyond established standards, including off-label strategies or clinical trial enrollment. Typically, MTBs discuss patients with advanced cancer for whom guideline-based standard treatment options are limited, nearing exhaustion, or already exhausted, and for whom comprehensive molecular profiling may identify additional therapeutic or trial options. MTB discussions are usually multidisciplinary, involving oncologists, pathologists, molecular biologists, geneticists, and other specialists as needed. In current routine practice, the board's recommendation is generally documented in a professional protocol and communicated to the patient by the treating oncology team during a subsequent consultation.

The structure of MTBs raises considerable ethical questions, including issues of access, uncertainty, and patient involvement.[7] Recent work has further highlighted communication challenges around comprehensive genomic profiling. A review concluded that patients often have high expectations that contrast with uncertain clinical benefit, emphasizing the role of transparent dialogue and shared decision-making in the context of molecular tumor boards.[8]

These challenges are also reflected in current MTB reporting practices. The standard MTB protocol is designed for healthcare professionals and usually incomprehensible for patients and their families. From a patient's perspective, this communication gap may cause distress and reinforce uncertainty. It may even induce negative expectations. Conversely, clear and accessible communication can promote understanding, strengthen patient empowerment, and enhance shared decision-making. International initiatives such as OpenNotes[9,10] and the European Medicines Agency's guidance on Good Lay Summary Practice demonstrate that plain-language medical documentation is both feasible and beneficial, yet such approaches have not previously been applied to molecular tumor boards.

To address this communication gap, the *MyCODE* study aimed to develop and evaluate a lay-friendly, patient-centered MTB protocol, co-created by oncologists, communication experts, and patient representatives. Our focus was on feasibility, acceptance, and perceived usefulness from both patient and physician perspectives.

# Patients and methods

## Study design and setting

*MyCODE* is a single-center, prospective study conducted at the West German Cancer Center (WTZ) of the University Hospital Essen, a large academic comprehensive cancer center in Germany.

## Study population

*MyCODE* included adult patients with cancer referred to the MTB of WTZ Essen. Patients were prospectively enrolled between November 2024 and June 2025. Inclusion criteria were signed informed consent within the German MII Broad Consent framework, presentation to the MTB, age $\geq$18 years, and sufficient ability to comprehend written information in German. All patients included in this study had advanced cancer and were referred to the MTB in a later-stage non-curative setting, typically when guideline-based standard treatment options were nearing exhaustion or had already been exhausted. The planned total sample size was $>$30 patients to receive feedback on the *MyCODE* protocol. To this end, patients were enrolled until at least 30 responses were received. As this was a prospective feasibility and acceptance study of a newly developed intervention in routine clinical care, no formal a priori sample size calculation was performed. Instead, the sample size was pragmatically defined to obtain at least 30 completed patient questionnaires, which was considered sufficient for an initial descriptive evaluation of feasibility, acceptance, and perceived usefulness.

## Study procedures

Patients were referred to the MTB as part of clinical routine. Alongside the standard MTB protocol, a lay-language protocol (*MyCODE* protocol) was prepared by the attending MTB oncologist. The protocol was written following a standardized framework co-created by MTB physicians, psychologists, and the WTZ patient advisory board. The lay-language protocol was handed out during the consultation following the MTB discussion. Approximately 7–10 days later, patients received study-specific questionnaires by mail.

During the study, a total of 13 physicians involved in oncological care were asked to distribute protocols to their patients. These physicians were also invited to complete a dedicated questionnaire regarding the usefulness and feasibility of the

lay-language protocol. Questionnaires were returned anonymously in order to reduce personal bias, as all physicians were personally known to the study lead.

Primary endpoints were patient-reported assessments specific to the lay language protocol. Domains included perceived need, feasibility, acceptability, usefulness, comprehension, empowerment, decision support, and emotional response.

Secondary endpoints were clinician-reported assessments of the same protocol. Domains included perceived patient benefit, utility during consultations, adequacy of structure, content and wording, and intention to use in routine care.

## Patient protocols

A standardized framework was developed to transfer MTB content into patient-friendly language. The framework followed psychological and didactic principles derived from recommendations on physician-patient communication good lay summary practice, as well as from research on treatment expectations.[11–15] A plain-language approach was implemented with the following characteristics:

- Use of jargon-free, simple language with short sentences.
- Necessary technical terms were introduced with a plain-language cue such as "*This is called …*".
- Clear content structure was ensured with signposting and ordering cues.
- Explicit connectors (eg, because, if, although, consequently) were used to clarify reasoning and relationships.
- Elements of storytelling were utilized to improve patient engagement.
- If clinically possible, a realistic-positive message and probability framing were used while words signaling inappropriate uncertainty and vagueness, as well as negative suggestions, were avoided to reduce negative expectations and fear. For example, in cases without a molecularly matched treatment recommendation, wording was used that clearly communicated this limitation while explicitly avoiding the impression that no further treatment options existed beyond the molecular findings.
- Overall, the protocols aimed to balance conciseness with completeness to avoid information overload while maintaining an engaging, yet professional tone.
- An appendix with extra information on diagnostics and molecular tumor boards was included, intended for patients who wish for further information.

To illustrate the structure, content, and lay-language translation approach of the MyCODE protocols, an anonymized example of a patient protocol has been included in the Supplementary Material.

From the outset, the study was co-developed with the WTZ patient advisory board and the DFG-funded CRC 289 "Treatment Expectation." Patient input was particularly influential in writing the study protocol, designing the framework for the patient protocol and questionnaire. This input was gathered using a mixed-methods approach involving structured questionnaires and semi-structured interviews (will be reported separately).

## Assessment instruments

All questionnaires were handed out in German. Patient questionnaires covered sociodemographic assessment, communication experiences, personal use and evaluation of the lay-language protocol, and free-text responses. Physician questionnaires assessed perceived utility, feasibility, structure, language, and attitudes regarding protocol provision. As validated tools for assessing patient-friendly MTB protocols were not available, we built upon a validated questionnaire on patient acceptance of lay-language discharge letters.[16,17] By adapting selected items from this instrument to the MTB context, we aimed to remain as close as possible to an established and conceptually validated tool. As no tool was available for physicians' evaluation, we self-created a questionnaire based on items of interest regarding further development of patient protocols. Full patient and physician questionnaires are provided in Tables 1-4 and Figures 1 and 2. Questionnaires were originally developed in German and translated for publication.

## Statistical analyses

All statistical analyses were performed using IBM SPSS Statistics, version 29.0 (IBM Corp., Armonk, NY, USA). Descriptive statistics were used to summarize patient characteristics and patient/physician questionnaire responses (absolute and relative frequencies, percentages). Median and range were calculated for age. Exploratory patient subgroup comparisons (by presence of a therapeutic recommendation, age group $<65$ vs $\geq 65$ years, and gender) were conducted using Pearson's $Chi^2$-tests to test differences in frequencies. Likelihood ratio or Fisher's exact tests were applied in case of small expected differences. A two-sided $P$-value $<.05$ was considered statistically significant. Exploratory comparisons were not conducted for the group of physicians due to the small sample size and given that sociodemographic data were not collected to maintain anonymity and to reduce personal bias.

## Data management and ethics

Data were anonymized and stored securely on institutional servers, with retention for a maximum of 10 years. Results are only reported in aggregate form. The study was approved by the responsible ethics committee (ethics committee University Hospital Essen, 24-12093-BO). The study was registered at the German clinical trials platform DRKS (Deutsches Register Klinische Studien, DRKS00037120).

# Results

Forty-three patients received a lay-language MTB report. 33 patients (18 women, 15 men) completed and returned the questionnaire. Patient characteristics are summarized in Table 1. 18 patients (55%) had cancers of the pancreas or biliary tract, reflective of the patient population of the WTZ MTB. Table 2 provides an overview of patient-reported information obtained from the patient questionnaire. Most patients lived with at least one other adult household member, while five (15%) reported children in their household and seven (21%) lived alone.

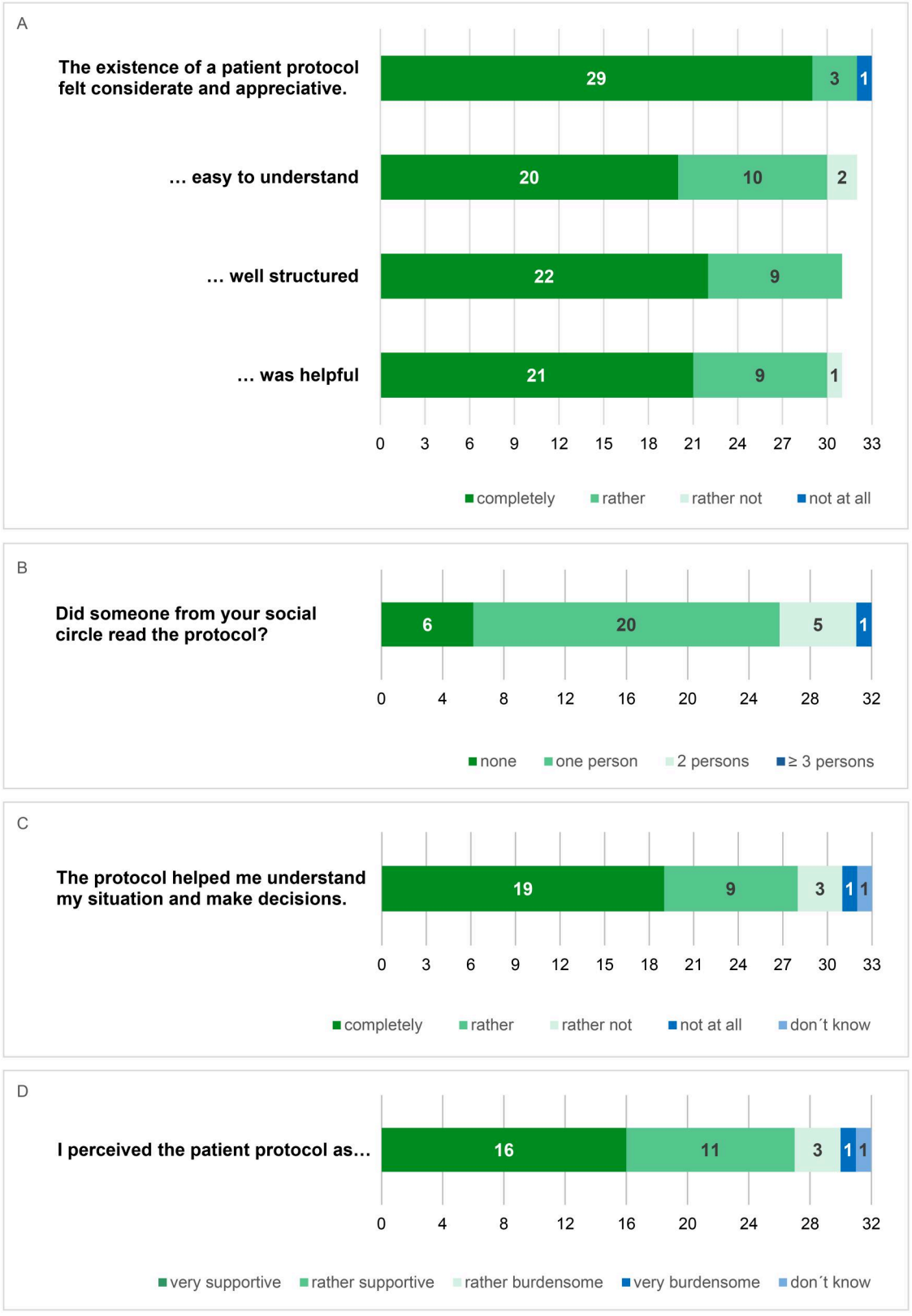


**Figure 1.** Depiction of key questions and answers from patient questionnaires.

The median age was 65 years (range: 38-83). 82% of participants were native German speakers. Educational backgrounds were heterogeneous: 3% had no degree, 18% completed elementary/lower secondary school, 15% intermediate secondary school, 6% upper secondary school, 27% vocational training, and 30% had a university degree. Additionally, 6% of patients reported

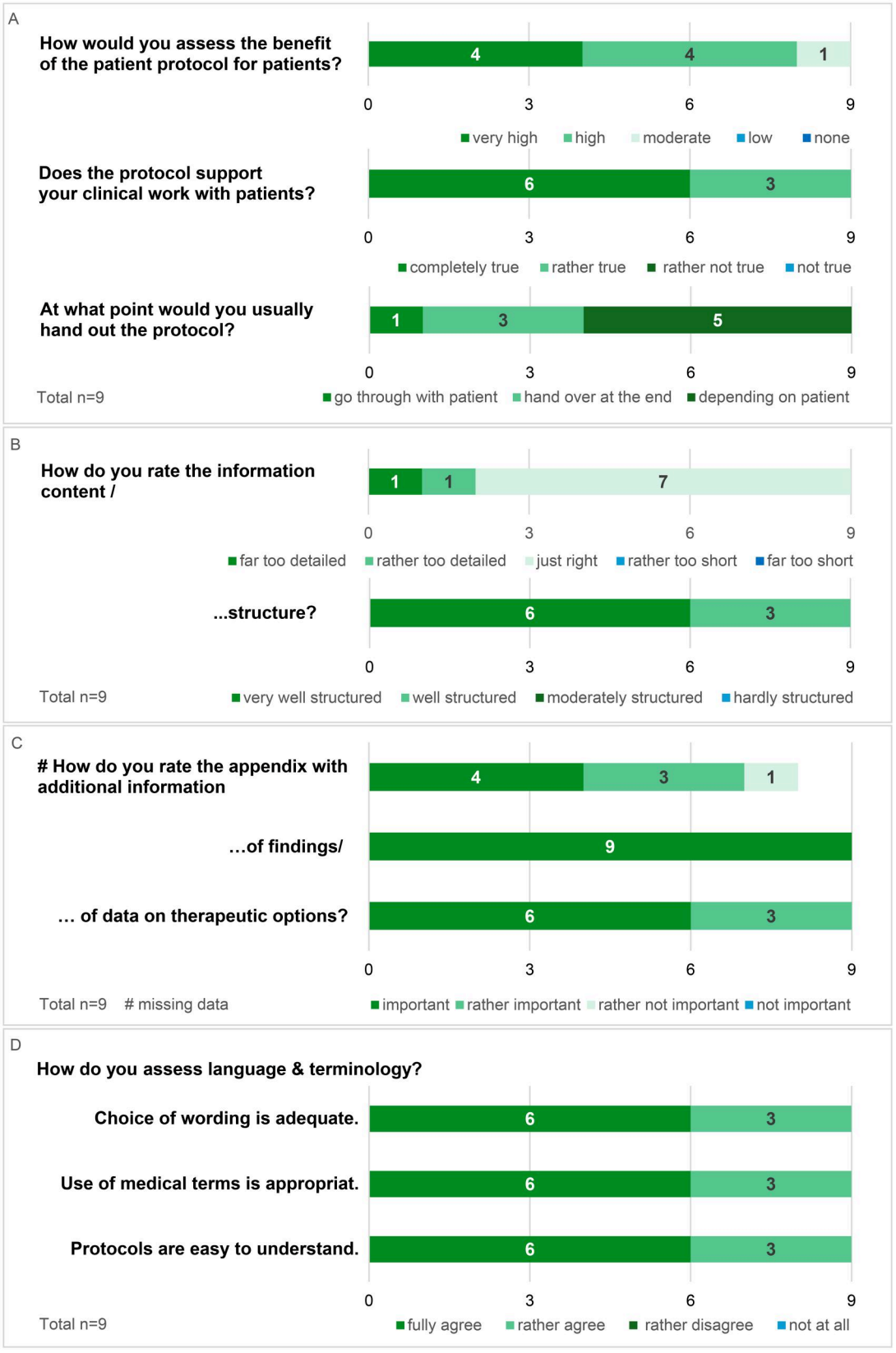


**Figure 2.** Depiction of questions and answers from physician questionnaires.

working in a healthcare profession. Of the ten patients who did not return the questionnaire, 70% were men, the median age was 64 years (range: 29-71), and 90% had pancreatic or biliary tract cancer. Among survey responders, 17 of 33 patients (52%) had received a recommendation for molecularly targeted therapy, whereas 7 of 10 non-responders (70%) had not received such a recommendation.

Patient perceptions of consultations prior to receipt of the patient protocol are shown in Table 3. 47% reported a detailed discussion of diagnostic expectations with their oncologist, 44% a brief discussion, and 6% no discussion. Regarding therapeutic consequences, 88% reported that they had received information, while 6% did not and 6% could not recall. Results were discussed in detail in 36% of cases, briefly in 49%, and not at all in 15%. Explanations were considered completely understandable by 59% of patients, rather understandable by 33%, and not understandable by 4%; one patient (4%) stated that no explanation was required. Almost all patients reported to be involved in treatment decisions as much (71%) or rather as much (26%) as they wished.

The data on use and evaluation of the patient protocol are summarized in Table 4 and Figure 1. All patients read the protocol, 90% thoroughly and 10% only briefly. 91% discussed the protocol with others (Table 4). 82% stated that someone from their social circle also read the protocol: 63% shared it with one person, 16% with two, and 3% with three or more; 18% did not share the protocol (Figure 1B). The protocol was judged

**Table 1.** Patient characteristics.

| Variables | Survey responders *n* (%) | Survey non-responders *n* (%) |
|---|---|---|
| **Female** | 18 (55) | 3 (30) |
| **Male** | 15 (45) | 7 (70) |
| **With recommendation** | 17 (52) | 3 (30) |
| **Without recommendation** | 16 (48) | 7 (70) |
| **Diagnosis** | | |
| **BTC** | 11 (33) | 5 (50) |
| **PDAC** | 7 (22) | 4 (40) |
| **GEJ** | 2 (6) | 0 |
| **Melanoma** | 2 (6) | 0 |
| **Sarcoma** | 2 (6) | 0 |
| **NSCLC** | 1 (3) | 0 |
| **NEC** | 2 (6) | 0 |
| **Breast cancer** | 2 (6) | 0 |
| **Cervical cancer** | 1 (3) | 0 |
| **CUP** | 3 (9) | 0 |
| **UC** | 0 | 1 (10) |

Abbreviations: BTC, biliary tract cancer; CUP, carcinoma of unknown primary; GEJ, gastroesophageal junction carcinoma; NEC, neuroendocrine carcinoma; NSCLC, non-small cell lung cancer; PDAC, pancreatic ductal adenocarcinoma; UC, urothelial cancer. Total $N = 33$ who completed the survey; $N = 10$ who did not complete the survey.

**Table 2.** Patient questionnaire: patient characteristics ($N = 33$).

| Question (translated) | Categories | *n* (%) |
|---|---|---|
| **Do you live alone?** | Yes | 7 (21.2) |
| | No | 26 (78.8) |
| **If no: Number of cohabitants <18**[a] | 0 | 21 (80.8) |
| | 1 | 3 (11.5) |
| | 2 | 1 (3.8) |
| | 3 | 1 (3.8) |
| **If no: Number of cohabitants ≥18**[a] | 0 | 2 (7.7) |
| | 1 | 19 (73.1) |
| | 2 | 3 (11.5) |
| | 3 | 2 (7.7) |
| **Is German your native language?** | Yes | 27 (81.8) |
| | No | 6 (18.2) |
| **Please indicate your highest educational level** | No degree | 1 (3.0) |
| | Lower secondary (Hauptschule) | 6 (18.2) |
| | Intermediate secondary (Realschule/POS) | 5 (15.2) |
| | Upper secondary (Gymnasium/EOS) | 2 (6.1) |
| | Vocational training | 9 (27.3) |
| | University | 10(30.3) |
| **Do you work in a healthcare profession?** | Yes | 2 (6.1) |
| | No | 31 (93.9) |

[a] Only patients who do not live alone ($n = 26$).

**Table 3.** Patient questionnaire: physician-patient consultation prior to protocol ($N = 33$).

| Question (translated) | Categories | *n* (%) |
|---|---|---|
| **Did your physician discuss expectations regarding molecular diagnostics before MTB referral?**[b] | Detailed | 15 (46.9) |
| | Brief | 14 (43.8) |
| | None | 2 (6.3) |
| | Don't know | 1 (3.1) |
| **Did your physician explain that the diagnostics may not yield a new treatment option?**[b] | Yes | 28 (87.5) |
| | No | 2 (6.3) |
| | Don't know | 2 (6.3) |
| **Were the MTB results discussed with you?** | Detailed | 12 (36.4) |
| | Brief | 16 (48.5) |
| | None | 5 (15.2) |
| **If yes: Were the results explained in an understandable way?**[a] | Completely | 16 (59.3) |
| | Rather | 9 (33.3) |
| | No | 1 (3.7) |
| | No explanation required | 1 (3.7) |
| **If yes: Did you have unanswered questions afterwards?**[a] | Yes | 4 (15.4) |
| | No | 17 (65.4) |
| | Don't know | 5 (19.2) |
| **Do you feel adequately involved in treatment decisions?**[b] | Yes, as I wish | 22 (71.0) |
| | Rather | 8 (25.8) |
| | No | 1 (3.2) |
| | I do not wish to be involved | 0 |

[a] Only patients who answered "detailed" or "briefly" in question 9; question 10 ($n = 27$), question 11 ($n = 26$).
[b] Missing data.

**Table 4.** Patient questionnaire: use and evaluation of structure/content of patient protocol ($N = 33$).

| Question (translated) | Categories | *n* (%) |
|---|---|---|
| **Did you read the patient protocol?**[a] | Thoroughly | 28 (90.3) |
| | Briefly | 3 (9.7) |
| | Not at all | 0 (0) |
| **Did you discuss the protocol with others?**[a] | Yes | 29 (90.6) |
| | No | 3 (9.4) |
| **The overall amount of information was …**[a] | Far too detailed | 1 (3.1) |
| | Somewhat too detailed | 2 (6.1) |
| | Just right | 28 (87.5) |
| | Somewhat too short | 1 (3.1) |
| | Far too short | 0 (0) |
| **Explanations of findings are …**[a] | Important | 30 (93.8) |
| | Rather important | 2 (6.3) |
| | Rather not important | 0 (0) |
| | Not important | 0 (0) |
| **The appendix … … was useful**[a] | Completely | 17 (53.1) |
| | Rather | 12 (37.5) |
| | Rather not | 1 (3.1) |
| | Not at all | 0 (0) |
| | Don't know | 2 (6.3) |
| **… should be expanded** | Completely | 6 (20) |
| | Rather | 9 (30) |
| | Rather not | 11 (36.7) |
| | Don't know | 4 (13.3) |
| **If no new therapy option was available, a patient protocol should …** | Still be provided | 31 (93.9) |
| | Not be provided | 2 (6.1) |

[a] Missing data.

completely helpful or rather helpful by 97% of patients, well-structured or rather well structured by all, and easy to understand by 94% (Figure 1A). The overall length was considered "just right" by 88% of patients, while 9% found it too long and 3% too short. The explanation of findings was rated important or rather important by all patients. The appendix was deemed useful by 91% of patients, and half (50%) felt it should be further expanded (Table 4).

The perceived impact of the patient protocol was assessed by evaluating the impact of taking a written explanation home. Thus, most patients reported that the protocol improved their understanding of treatment decisions (85%), with 58% answering "completely" and 27% "rather" (Figure 1C). Emotional impact was described as supportive by 84% of patients, including 50% "very supportive" and 34% "rather supportive," while 12% reported it as burdensome and 3% as very burdensome (Figure 1D). Almost all patients (97%) stated that the existence of a patient protocol felt considerate and appreciative (Figure 1A), and 94% stated that they would want to receive such a protocol even if no new therapeutic option was available (Table 4).

Free-text comments further underscored the value of receiving a personalized document. Patients emphasized appreciation of clear explanations and the personal approach. The possibility to re-read the protocol for better understanding and to share it with family members was repeatedly and positively mentioned.

Additional subgroup analyses explored differences in the perception of the protocols. Putative differences were assessed for receiving a therapy recommendation (yes/no), age (<65 vs ≥65 years), and gender (men/women). No significant differences were observed between patients who received or did not receive a therapy recommendation. Age-related differences were also not observed. However, several gender-related differences were significant: women more frequently rated the protocol as helpful ($P = .048$), well structured ($P = .036$), and easy to understand ($P = .035$) and considered the appendix useful ($P = .012$). All other comparisons were non-significant. Results from exploratory subgroup analyses by therapy recommendation, age, and gender are summarized in Table S1.

Additionally, treating physicians of the patients included in the study were asked for feedback. Of 13 physicians asked for feedback on patient protocols, ten were experienced fellows or board-certified physicians in medical oncology, two in gynecology and one in dermatology. Nine of these physicians (69%) returned completed questionnaires. Physicians' evaluations are summarized in Figure 2. Eight physicians rated the benefit for patients as high (44%) or very high (44%), and all nine physicians were supportive (67%) or rather supportive (33%) for their personal work. Seven (78%) also considered it to be useful for primarily treating oncologists or general practitioners. The amount of information was considered as "just right" by 7 (78%), while 2 (22%) considered it too detailed or far too detailed. All physicians rated the structure and comprehensibility as good or very good. The majority (88.9%) of physicians thought that the patient protocol should also be issued if no therapeutic recommendation was available.

# Discussion

*MyCODE* aimed to develop and evaluate a lay-language, patient-centered MTB protocol. In this single-center prospective study, lay-language protocols ("*MyCODE* protocol") were found to be highly accepted by patients and perceived as helpful, well structured, and easy to understand. Most patients read their individual protocol carefully and discussed it with at least one other person, and almost all considered take-home explanations important even when no targeted treatment option was available. The protocols were experienced as emotionally supportive by the majority, and patients reported feeling better able to understand their situation and participate in decisions. Exploratory analyses suggest that ratings are broadly consistent across age groups and independent of whether a treatment recommendation was present or not. Gender seemed to influence rating slightly, as women tended to rate the protocol higher than men in some items. Response rates in questionnaire-based oncology studies vary considerably depending on study design and patient population. As in other questionnaire-based oncology research,[18–23] participation may have been influenced by clinical context and individual patient burden. In our cohort, non-responders more often had no MTB recommendation for molecularly informed therapy and were disproportionately male, which may have affected subgroup patterns and should be

considered when interpreting these exploratory findings. These exploratory analyses are limited by small subgroup sizes and should be considered hypothesis-generating rather than confirmatory. Treating physicians rated the protocols as helpful for patients, their own work, and further medical care providers.

These findings indicate that standardized, patient-facing translation of MTB content has the potential to bridge a critical communication gap inherent to precision oncology. Such framing is aligned with shared decision-making principles and may mitigate uncertainty and negative expectations while supporting constructive treatment expectations and informed consent processes.[11–13] The high proportion of patients who shared the documents with relatives and partly also with further physicians underscores its value as a communication aid and suggests potential benefits for continuity of care with community providers.

Rohrmoser et al.[24] demonstrated that patients often have high expectations towards molecular testing, accompanied by uncertainty and emotional ambivalence. In their study, participants described transparent and respectful communication as a key factor contributing to their sense of being valued and understood. This aligns well with the results of the *MyCODE* study. Providing structured, comprehensible feedback, as implemented in the *MyCODE* protocol, may therefore help to align expectations with realistic outcomes and support constructive engagement in the clinical process.

While MTBs are now embedded in many comprehensive cancer centers,[5] patient-facing outputs remain rare and heterogeneous.[8] Our approach adds a multidisciplinary, participatory co-design including a patient advisory board and communication experts, as well as a standardized language and layout framework that can be replicated across indications. The consistently high ratings for comprehensibility and structure in our cohort support the validity of this framework.

Our finding that patients who did not receive a therapy recommendation rated the lay-language protocol as positively as those with a recommendation is noteworthy. This observation is in line with the strong recommendation of our patient advisory board to provide the protocol to all patients, including those without options. From a psychological perspective, transparent communication and acknowledgment can strengthen patients' sense of being valued, even in difficult clinical situations. This aligns with work on communication and patient empowerment.[25–29]

Further, exploratory analyses indicate that women tend to rate the protocol slightly more positive when compared to men. This finding is consistent with literature reporting gender-related differences in communication styles and patient expectations.[30] In contrast, we did not observe differences by age. Other studies suggest that older patients may face more challenges regarding health literacy.[31] In our study, patients below the age of 65 and of at least the age of 65 did not show any rating differences. Our sample included only four patients above the age of 75, of whom only one patient was above 80 years of age, which limits the generalizability of our results.

Physicians' responses in this study align with previously reported attitudes toward lay-language communication. Similar to surveys on patient versions of clinical guidelines and open medical records, most physicians in our study emphasized the supportive value of such materials for communication and patient understanding, while only a minority expressed concerns about excessive detail or possible misunderstandings. International studies show that once implemented, accessible patient information can enhance transparency and shared decision-making without increasing physicians' workload or documentation burden.[9,32,33] The participating physicians consistently rated the structure and comprehensibility of the *MyCODE* protocol as positive. It seems especially noteworthy that physicians and patients both largely agree that patients should receive protocols even if no therapeutic recommendation is available. Due to the limited number of physicians, these findings must be considered as exploratory and interpreted with caution. Overall, the physician feedback supports the feasibility and acceptability of integrating patient-adapted molecular tumor board protocols into routine oncology workflows and provides an initial signal of professional acceptance.

Our findings complement previous efforts to improve lay-language medical communication. In Germany, easy-to-understand discharge letters have been shown to be feasible, well accepted, and amenable to systematic evaluation.[16,17] Internationally, initiatives such as OpenNotes,[9,10] Good Lay Summary Practice for clinical trial communication,[15] and patient versions of clinical guidelines[34,35] have highlighted the broader value of accessible medical information. More recently, technological approaches such as PharmMT, Paper Plain, and MeDiSumQA have explored automated or semi-automated simplification of medical content.[36–38] Against this background, *MyCODE* extends these principles to the highly specialized and uncertainty-laden context of molecular tumor boards, where patient-facing communication has so far remained rare and heterogeneous.[5,8]

Prior work suggests that patients value multidisciplinary cancer conferences and wish to be informed about their outcomes, including in written form[39]. Earlier observational studies also indicated that patient preferences were often only sparsely represented in tumor board discussions, highlighting a broader communication gap that may be even more pronounced in the highly specialized MTB setting.[40]

Direct patient involvement in tumor board discussions has not been implemented systematically. Cannon et al.[41] explored patient participation in MTB discussions as a model of maximal transparency, but the highly specialized and time-constrained nature of MTBs limits broader implementation. In a related but less complex setting, Diekmann et al.[42] described mixed patient experiences with participation in breast cancer multidisciplinary tumor conferences, including difficulties in following the discussion. This is noteworthy, as MTBs usually involve even more complex molecular findings and treatment decisions in patients with largely exhausted standard therapies. Our approach may therefore offer a more feasible alternative, balancing transparency with practicality.

Strengths of the study include the prospective, real-world implementation, systematic assessment using standardized questionnaires, and the inclusion of both patient- and physician-relevant endpoints. The design was intentionally pragmatic to minimize disruption of routine workflows. As a prospective feasibility and acceptance study of a newly developed intervention in routine clinical care, the study was not designed or powered for formal hypothesis testing; rather, the sample

size was pragmatically defined to enable an initial descriptive evaluation. Limitations therefore include the single-center setting, modest sample size, and reliance on self-report measures without external validation or longitudinal follow-up. The questionnaires were tailored to this intervention and require formal psychometric validation in larger, diverse cohorts. Selection and non-response biases cannot be excluded; the observed proportions should therefore be interpreted descriptively. In particular, non-responders more often had no MTB recommendation for molecularly informed therapy, suggesting a potential response bias. In addition, non-responders were disproportionately male, which may have influenced the gender distribution of the respondent group and should be considered when interpreting gender-related patterns. Clinical variables such as disease stage or performance status may also influence how patients perceive and understand lay-language MTB information. Although all included patients were in an advanced palliative treatment situation and the overall clinical context was therefore broadly comparable, a potential bias related to differences in individual clinical condition cannot be excluded. Given the limited sample size of this pilot study, these factors could not be meaningfully explored and should be addressed in future larger-scale evaluations. More broadly, response rates in questionnaire-based oncology studies are often moderate, particularly in clinically vulnerable populations.[18–23] Regarding the physician questionnaires, we aimed to reduce the possibility of bias due to personal connections by allowing for anonymous return of the questionnaires. However, social desirability bias cannot be completely ruled out.

Future studies should assess lay-language MTB protocols in larger and more diverse cohorts, include multicenter and longitudinal evaluation, and further validate the assessment tools used in this setting. In addition, our ongoing work[43] explores whether AI-supported drafting could support broader implementation of such protocols in routine care while preserving physician oversight and communication quality.

Taken together, our study provides evidence for the feasibility and acceptance of lay-language MTB protocols. These findings support the value of structured patient-centered communication in precision oncology and suggest that patient-friendly MTB protocols could become a meaningful component of routine care.

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## Author contributions

Ina Pretzell (Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Validation, Writing—original draft), Anke Fleischhauer (Conceptualization, Data curation, Investigation, Methodology, Project administration, Supervision, Validation, Writing—review & editing), Ilektra Mavroeidi (Resources, Writing—review & editing), Nicola Prasuhn (Methodology, Validation, Writing—review & editing), Katharina Kaminski (Methodology, Writing—review & editing), Noëlle Bender (Methodology, Writing—review & editing), Viktor Grünwald (Resources, Writing—review & editing), Jessica Holly (Resources, Writing—review & editing), Tina Hörbelt-Grünheidt (Visualization, Writing—review & editing), Tabea Pakull (Methodology, Writing—review & editing), Vivian Rosery (Resources, Writing—review & editing), Hendrik Schürmann (Resources, Writing—review & editing), Sebastian Bauer (Resources, Writing—review & editing), Jens T. Siveke (Resources, Writing—review & editing), Marcel Wiesweg (Resources, Writing—review & editing), Lisa Zimmer (Resources, Writing—review & editing), Dirk Schadendorf (Resources, Writing—review & editing), Martin Schuler (Resources, Supervision, Writing—review & editing), and Sven Benson (Conceptualization, Data curation, Formal analysis, Methodology, Supervision, Validation, Visualization, Writing—review & editing)

## Supplementary material

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## Conflicts of interest

The authors declare the following potential conflicts of interest: I.P.: received honoraria for advisory boards for BeOne and for lectures from Deutsche Bundesbank, NeoConnect and Daiichi-Sankyo. A.F.: no conflicts declared. I.M.: received honoraria from InCyte and art tempi Communications GmbH; received clinician scientist grant from University Medicine Essen Clinician Scientist Academy (UMEA), sponsored by the Faculty of Medicine; received travel grants from Pierre Fabre, BeOne, Jazz Pharmaceuticals. N.P.: no conflicts declared. K.K.: no conflicts declared. N.B.: no conflicts declared. V.G.: honoraria for lecture: Bristol-Myers Squibb, Ipsen, Eisai, MSD, Merck KGa, AstraZeneca, AAA/Novartis, Amgen, Johnson & Johnson, Teilx Pharmaceuticals, Gilead Sciences, Roche. Honoraria for advisory boards: Bristol-Myers Squibb, Pfizer, Novartis, MSD, Ipsen, Johnson & Johnson, Eisai, Debiopharm, Gilead Sciences, Oncorena, Synthekine, Recordati. Travel support: Pfizer, Johnson & Johnson, Merck KGa, Ipsen, Amgen. J.H.: received travel support from AbbVie and GSK. T.H.-G.: no conflicts declared. T.P.: no conflicts declared. V.R.: no conflicts declared. H. S.: received travel support from Servier. S.B.: received honoraria from Pharmamar, Deciphera, Springworks; served as consultant or had advisory role for Blueprint Medicines, Deciphera, Boehringer Ingelheim, IDRX, Adcenco, Merck; received travel support from von Pfeffel Pharmaceuticals. His institution received research funding from IDRX, von Pfeffel Pharmaceuticals.

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## Data availability

The data that support the findings of this study are not publicly available due to privacy and ethical restrictions. Anonymized data may be made available from the corresponding author upon reasonable request and with permission of the University Hospital Essen ethics committee.

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